

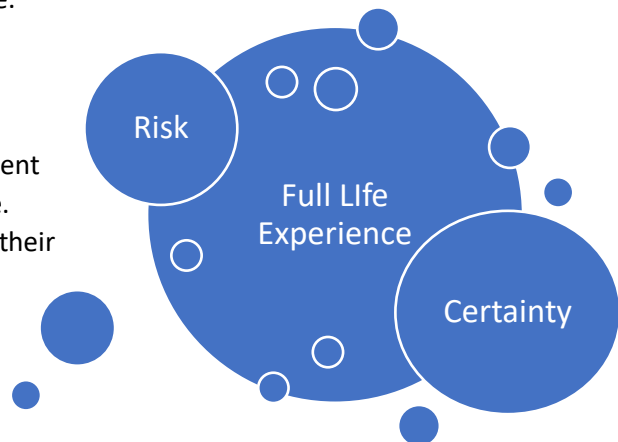
REFRAMING RISK: Are We Talking about Dignity of Risk for Dignity of Experience?

Rarely, in our conversations about dignity of risk, are we talking about activities that we would typically frame as “risky.” Experiences that are assumed to be typical for the rest of community, become burdened with the term of “risk” in the lives of people with intellectual and/or developmental disabilities (I/DD).

Changing our mindset about “risk” liberates us to do 2 things: 1) It liberates all of us to view people with I/DD as equals. With rights and responsibilities to live a full life. 2) It helps us better access “everyday” “real world” “just like the rest of us” solutions and creativity that can help us nurture and navigate the opportunities and experiences that comprise a full life.

REFRAMING SAFETY: Are We Seeking *Safety* or *Certainty*?

We, as a human service community, have a commitment to foster safety and a sense of safety in a person’s life. Like all of us, people with I/DD must truly feel safe in their homes, their communities and within their relationships in order to experience a full life. Nothing in this paper should be construed as minimizing this responsibility. However, in human services, we may frame a discussion in terms of *safety*, when what we are seeking is *certainty*. This is understandable: we want predictability in our services and we want some sort of reassurance that if we try something new, we’ll experience good outcomes.



We owe it to the people we serve to be honest with ourselves about what we are seeking and analyze circumstances accordingly. If we are wanting reassurances that “nothing bad is going to happen” when supporting a person to otherwise have a typical life experience, we are placing a burden of “certainty” on a person that we do not experience in our own lives. If we are instead asking, “how can we help plan with a person to minimize bad things happening?” then we are more effectively striking the balance between our obligation to support people’s experience and our responsibility to ensure people feel safe.

WHAT THE RESEARCH SHOWS

Researchers have found with regularity that when a person with I/DD has opportunity to choose and try important and meaningful life experiences, they have a higher quality of life. Engagement in fulfilling experiences and activities is related to higher self-efficacy and higher likelihood for community belonging and the development of important social relationships outside of their family and paid support.

At the same time, national studies show that choice and experience are often limited for people with disabilities. Recent data from the National Core Indicators shows that, on average, only half of the adults with disabilities interviewed (52%) choose their daily schedules and about 2/3 (69%) choose how they spend their free time. Researchers have also found that there are factors that further impact people’s experiences, including:

Supporting the Dignity of Experience

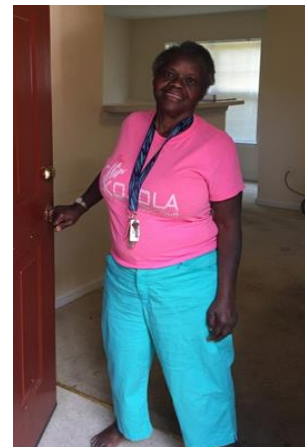
- **Where people receive services:** According to several studies, the more segregated the service setting, the fewer opportunities a person with disabilities has to choose their experiences.
- **How people get their money:** A recent study found that people who are dependent only on public funding as a sole source of income, tend to have less choice, control and experiences in their lives.
- **Beliefs and practices of service providers:** A recent study from the United Kingdom, studying the outcomes and experiences of adults with disabilities who had moved from a traditional, congregate service to a more individualized self-directed service were not more likely to have meaningful experiences because of the service change alone. For people to have more meaningful experiences, the beliefs and practices of the people who supported the person had to adapt practices to support people in choosing and experiencing new things.
- **Beliefs and practices of families:** Researchers have also found that families are among the most important facilitators of experience, as today, more than 70% of people with disabilities live with their families in the United States. Many families have caretaking roles to support their family members, studies have found that how families conceptualize their roles impacts the experiences that their family members have. Families who feel their job is to protect their family members tend to be less enthusiastic about taking risks than those who have a different role.

PERSONAL EXPERIENCES

BARBARA

Barbara has received NC Innovations Waiver services for almost two decades. She has lived in institutional settings, congregate living arrangements, and an alternative family living (AFL) setting in the past. She was living in a congregate arrangement through the Residential Supports service in the NC Innovations Waiver. She wanted to live in her own apartment, and this became available through Supported Living.

Barbara moved into her own apartment in West Asheville, through the Key Program available through the NC Housing Finance Agency using Supported Living Service Level 2. Because of Barbara's level of behavioral and health care support needs, she received 12 hours of staff each day and had an alarm system on her doors to keep her from being vulnerable to others when staff was not with her. Barbara did not like having this level of staffing so ways to reduce staffing were explored. Technology was the answer. After assessments, Simply Home installed non-intrusive monitoring equipment (sensors, timers, verbal prompting equipment, etc.) in Barbara's apartment. The introduction of technology increased Barbara's opportunity for experience and reduced staffing. She now requires staffing only 6 to 7 hours per day mostly



Supporting the Dignity of Experience

to support her employment and loves her free time in her own home. Barbara has been employed with the Town of Black Mountain for 8 years.

She has made community connections in her apartment building, has control over her money, how she spends it, where she shops, and is able to live comfortably. She is living a healthy lifestyle (frequents the YMCA for exercise and socializing) and for the first time in more than 20 years, her diabetes is controlled with her diet and exercise. She has lost a significant amount of weight and says she feels “great.” Her success is likely tied to this opportunity for autonomy.

JENNIFER

Jennifer is living in her own apartment through the NC Innovations Supported Living Service. She receives Level 3. She grew up in her family home and was living in a 6-bed group home before moving to her apartment. Jennifer chooses to have a housemate to share time and



expenses. She lives with a friend of hers who also receives services. Both women express their happiness and satisfaction in sharing an apartment.

Jennifer uses a wheelchair and has complex medical support needs. She needs someone available 24/7 to assist with mobility and activities of daily living functions. Her roommate serves as a support when staff is not scheduled. Jennifer likes relying on a friend instead of a paid support because this increases her autonomy.

Jennifer is very social and likes to fill her days with activities that are meaningful to her. She is upbeat, loves to go to the Drum Circle in downtown Asheville on Friday evenings, and is an avid Asheville Tourists minor league baseball team fan. Jen also enjoys music, and particularly likes live concerts. Non-intrusive monitoring technology is installed in her apartment, and staff is available to respond within an hour if necessary.

TAMMY

Tammy and her husband live in an apartment with their three cats. Tammy has been receiving NC Innovations Waiver Services for over 14 year. When the Supported Living Service became available through the NC Innovations Waiver. Tammy was living in a 6-bed group home separate from her husband. Tammy intellectual disabilities, mental health and substance use disorders, and physical health issues. She needs supports from a multi-faceted team to maintain her mental and physical health, as well as navigating social interactions and relationships.

Supporting the Dignity of Experience

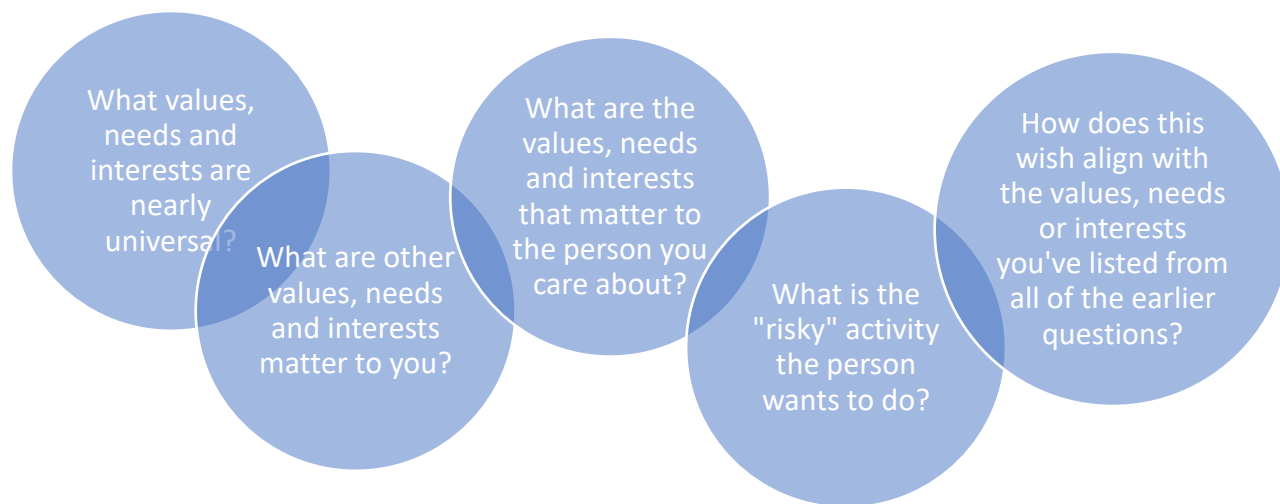
Tammy moved into an apartment with her husband in March 2017 using Supported Living Level 2 services. The provider agency had numerous challenges retaining staff, finding good staff matches and retaining direct support professionals for Tammy but managed to ensure her needs were met. Tammy's husband provides natural support, but the support he can provide is limited.

When Tammy lived in the group home, she often had issues with wanting to smoke cigarettes in the home. This was usually a matter of contention with staff because she did not like being required to go outside to smoke. The apartment that Tammy moved into in March 2017 was a non-smoking apartment. For a while, Tammy adhered to the non-smoking rule. However, she started breaking this rule and after several warnings, the landlord decided to evict her and her husband because she continued to smoke cigarettes in the home.



Tammy was greatly upset by eviction. So, was her husband. The eviction made it difficult to find another home. However, the provider agency managed to find a home that allowed Tammy's three cats and did not limit smoking cigarettes. Tammy has been educated numerous times about the dangers of cigarettes but chooses to continue smoking, which is her right as an autonomous adult.

A SELF-REFLECTION: How do I feel about this?



LET'S TALK ABOUT IT: ACTIVITIES WITH OTHERS

ACTIVITIES WITH OTHERS, PART I: TALKING ABOUT HOW WE LIVE

- **Goal of this Activity:** To encourage dialogue about how we as citizens make life choices and pursue life experiences.
- **Guidance on Activity:**
 - This activity can involve any group supporting a person, but may be most useful with direct support staff and managers.
 - If the group is thinking about a particular person's situation, including the person in this discussion is strongly encouraged.
 - Depending on the size of the group and the time available for the activity, you can have one extended conversation or divide the conversation over several meetings.
 - Encourage open conversation: choose a comfortable space and commit to keeping information shared confidential.

ACTIVITY WITH OTHERS, PART I:			
	The Conversation Starter	The Follow Up Questions	Take Aways and Next Steps
Conversations about Experiences	Along with others in the group, in a few sentences, describe an enriching life experience that you have either had or hope to have. This can be anything, but some examples: buying your own home, getting married; pursuing a particular job; going on a trip; learning a new skill, etc.	What motivated you to pursue this experience? What anxieties (if any) did you have? How did you overcome them? What supports did others provide (from concrete activities to simple encouragement)? What would/did you say to people who discouraged you?	What common themes emerged from individual stories?
Conversations about Mistakes	Along with others in the group, in a few sentences, describe a time when you tried something and failed or had an error in judgment.	What lessons did you learn? If you had the experience again, are there things you would do differently?	What common themes emerged from individual stories?
Conversations about Risk	Along with others in the group, in a few sentences, describe a time when you pursued something "risky" and it worked out? Describe a time when you pursued something "risky" and it didn't work out?	What made each activity feel "risky?" What lessons did you learn from each?	What common themes emerged from individual stories?

	The Conversation Starter	The Follow Up Questions	Take Aways and Next Steps
Conversations about Support	Along with others in the group, in a few sentences, describe how others best help you when thinking through how to engage in an activity, pursue a goal	How do you determine how much support you want and need in pursuing a new activity or goal? When you feel well supported to pursue something, what does that look like? What kind of “support” have others provided to you in the past that was NOT helpful? Why?	What kind of support do we provide the people we support to pursue new experiences? How is it the same or different from the support we want in our own lives?

ACTIVITIES WITH OTHERS, PART II: SUPPORTING OTHERS TO LIVE

Goal of this Activity: To DISCUSS ANXIETIES WE HAVE ABOUT SUPPORTING A SPECIFIC PERSON’S DESIRED EXPERIENCE AND TO BEGIN PLANNING FOR SUPPORTING THIS EXPERIENCE.

Guidance on Activity:

- This activity is targeted at the group of people who will be directly responsible for supporting the person in her experience. This group may be DSPs or a person’s team, including DSPs, family members and others.
- Including the person who is at the center of the discussion is strongly encouraged.
- Identify the “experience” that the group wants to discuss. Be specific in describing the desired activity. Think about what you understand to be the specifics of person’s anticipated experience, not just the general description. So instead of “Joanna wants to live independently,” a more specific example may be: “Joanna wants to move out of her family’s home and live in her own place with a cat. She still wants her DSPs and is ok having a roommate.”
- Once you’ve identified the specific experience to analyze, there are three steps to this activity. The instructions and applicable diagrams are outlined after this Guidance section.
 - Step 1: The “Rainbow of Experience” Discussion—assessing what type of experience the person is wanting.
 - Step 2: The “Worry Reflection”---acknowledging and discussing any anxieties we have about this experience.
 - Step 3: Preparing for the Experience: Appreciate, Communicate, Anticipate---working to move from anxiety to action in supporting a person’s experience.

Supporting the Dignity of Experience

ACTIVITY WITH OTHERS, Part II	
The “Rainbow of Experience”	Start by each group member privately reflecting on where s/he views the proposed experience on the continuum. Discussion Questions: Where did others in the group place the experience on spectrum? What was the rationale?
The Worry Reflection	Start by each group member privately thinking about his/her own anxieties. Discussion Questions: - How did others in the group respond? Were there common themes? - What are some steps or actions the group can take to minimize the need for this worry?
Preparing for the Experience: Appreciate, Communicate, Anticipate	Building off the reflections and insights that have emerged through earlier activities, reflect, as a group on the questions included in the “pie wheel,” starting with “Appreciate.” The goal of these questions is to help the group begin moving into the planning stage of supporting an experience.

The Rainbow of Experience: How would we define this activity if a person didn't have a disability?



Supporting the Dignity of Experience

The Worry Reflection: What are we worried about? How can we feel less worried?

I'm worried that if a the person "fails" in this experience, she could get hurt.

I'm actually not really worried and here is why: _____

I'm worried that if something goes wrong, I'll get in trouble.

I'm worried that we're giving her "false hope" that she can do this.

I'm worried about something else: _____

Preparing for the Experience: Appreciate, Communicate, Anticipate

Are we clear on why a person wants to have this experience?

What are the unmet needs, values or preferences this person's wish reveals?

If we were in this person's shoes, how would we hope others would respond?

Appreciate

How do we support a person to understand the dimensions of this experience-- both the good parts and the difficult parts?

Are there other people who have done this we can all talk to to help in our planning?

Are there ways we can "try out" something or otherwise learn about what the experience will be like?

Communicate

Anticipate

What supports can we put in place to help a person have the experience and alleviate some of our worries?

How can we best stay ahead of potential problems?

Who does the person trust in sharing her own anxieties, needs or concerns?

If things start going off course, how will we know it?

When things are going great, how can we nurture it?

DIGNITY OF EXPERIENCE: RESEARCH & RESOURCES

Bonardi, A. (2009). The balance between choice and control: Risk management in New Zealand intellectual

Braddock et al., 2016

Carr, S. (2011). Enabling risk and ensuring safety: Self-directed support and personal budgets. *Journal of Adult Protection*, 13, 122 – 136.

Kozma A, Mansell J, Beadle-Brown J. Outcomes in different residential settings for people with intellectual disability: A systematic review. American Association on Intellectual and Developmental Disabilities. 2009;114(3):193–222. doi: <http://dx.doi.org/10.1352/1944-7558-114.3.193>. [PubMed]

Mansell J, Elliott T, Beadle-Brown J, Ashman B, Macdonald S. Engagement in meaningful activity and “active support” of people with intellectual disabilities in residential care. *Research in Developmental Disabilities*. 2002;23(5):342–352.

Neely-Barnes, S. L., Graff, J. C., Roberts, R. J., Hall, H. R., & Hankins, J. S. (2010). “It’s our job”: Qualitative study of family responses to ableism. *Journal of Intellectual and Developmental Disabilities*, 48 (4), 245-258. DOI: 10.1352/1924-95556-48.4.245.

Reinders, H. S., Schalock, R. L. (2014). How organizations can enhance the quality of life of their clients and assess their results: The concept of QOL enhancement. *American Journal on Intellectual and Developmental Disabilities*, 119, 291-302.

Smull, M, Choice and ControlSDA, April 2017

Wehmeyer, M., & Shogren, K. A. (2016). Self-determination and choice. In N. N. Singh (Ed.). *Handbook of evidence-based practices in intellectual and developmental disabilities*. (pp. 561-584). Switzerland: Springer International Publishing.